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Factors Affecting Participation in the eRedBook: A Personal Child Health Record

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Abstract. A personal child health record called the eRedBook was recently piloted in the United Kingdom. A qualitative exploratory case study was used to examine how public health nurses engaged or recruited parents and what factors hindered participation. Interviews and focus groups were conducted with those implementing the eRedBook and those taking part in the pilot study. A range of project documentation was also reviewed. Thematic analysis using the framework approach was applied to draw out themes. Numerous socio-technical factors such as the usability of the software, concerns over data protection and costs, poor digital literacy skills and a lack of Internet connectivity emerged. These barriers need to be addressed before the eRedBook is implemented nationwide.

Keywords. personal health record, eHealth, digital health, child, pediatric, public health nurse, implementation

1. Introduction

The 'Red Book' is a paper based child health record in the United Kingdom (UK) where infant health, growth and development milestones from birth are documented. A digitized version called the 'eRedBook', which takes the form of a personal health record (PHR), was piloted in two National Health Service (NHS) trusts [1]. Public health nurses, known as Health Visitors (HVs), helped promote the platform to parents, sign them up to use it and document in it as they would the paper based version. This study seeks to illuminate the factors that hindered HVs in engaging and recruiting parents to the eRedBook. If these can be identified and addressed it will improve how the personal child health record is implemented nationwide [2].

2. Methods

A qualitative exploratory case study design was adopted. Ethical approval for the study was obtained from the University of Glasgow. Secondary analysis of interviews done

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with implementation staff (n=11) between October 2012 and August 2015 was performed. Two mixed focus groups were also conducted in April 2015 with parents (n=12) and HVs (n=10) involved in the pilot of the eRedBook. Project documentation including quarterly technical reports, recruitment reports and evaluation updates were also reviewed (n=32). Thematic analysis using the framework approach [3] was undertaken to draw out themes that specifically affected participation in the eRedBook.

3. Results

Several factors emerged which affected HVs ability to engage and recruit parents to the eRedBook, which are grouped into technological, social and health service.

1. *Technological*: The usability of some aspects of the eRedBook platform, especially the complexity of registering and setting up a new profile, made it difficult for HVs to enroll parents on the PHR. Another barrier to participation was the concern HVs and parents had over the security of children's health data if it is going to be held by a private multinational company and not governed by the NHS.

2. *Social*: The lack of high-speed broadband in some rural areas was a major stumbling block as were the hidden costs associated with the PHR, which meant some families couldn't afford the technical equipment or Internet service to access online tool. The digital divide was clearly evident in certain economically deprived communities where some HVs work.

3. *Health Service*: Poor digital literacy skills among HVs also hindered engagement with parents around the eRedBook. Both electronic and paper versions were run in parallel which doubled HVs workload, and the PHR was not integrated with IT systems in the NHS which made it difficult for HVs to prioritize the eRedBook with parents during busy clinical appointments and sign them up to use it.

4. Discussion

HVs had to adapt to numerous challenges when rolling out a personal child health record in community settings. These digital health engagement issues need to be addressed before the eRedBook can be implemented nationwide.

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